Reset, Reconnect, Rebuild.

Family Action Young Carers

healthwatch
Windsor, Ascot and
Maidenhead

family action

Contents

Background

Family Action Young Carers and Healthwatch Windsor, Ascot and Maidenhead partnered with Frimley Health and Care Integrated Care System (ICS) to support their engagement project- Reconnect, Reset, Rebuild. The aim of this project is to bring together people in communities across the Frimley area to spark conversations about health and wellbeing priorities. The information in this report will help Frimley ICS to identify what matters most to the residents of local care homes empowering them to better join up health and care services, to improve population health and reduce health inequalities.

Why is Frimley Heath and Care carrying out this engagement now?

Recent reports, such as the Darzi review and the recommendations from Grenfell, remind us of the urgency to listen and understand the needs of our communities, As the government's 10-year plan for the NHS takes shape, it is essential that it is rooted in and reflects the true needs of our communities. This is our chance to make it happen.

Previous engagement with young people by Family Action Young Carers found that adult healthcare services do not make the link that children of their patient's will likely have caring roles and are not passing on this information to children's social care to ensure they are supported. Young Carers report that they are routinely "left out of conversations" and having to handle difficult side effects when healthcare teams "don't inform us about medication or treatments" and yet, "we have adult responsibilities to care, family are discharged to us."

This was evidenced in the Royal Borough of Windsor and Maidenhead by a low referral rate for young carers assessments, with only 9 referrals being received from healthcare teams between April 2018 – March 2022.

Even where young carers are identified, assessment is a statutory requirement, but the provision of support is not. Where support is provided, this can be focused on activities, rather than addressing what has led to the child or young person having caring roles, and if these are appropriate.

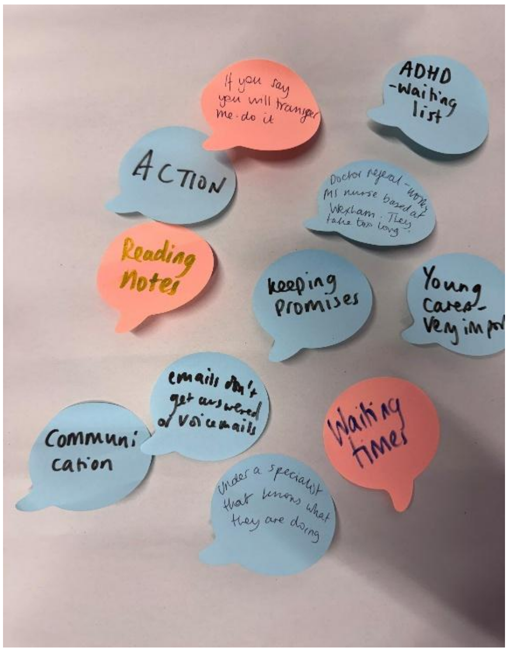
The Healthcare sector needs to be better linked with children's social care to inform them of children and young people's caring roles. Support services for young carers should go beyond the provision of activities and consider how to reduce inappropriate caring responsibilities. 7 of 10 carers start their caring journey in an NHS setting (Carers and Hospital Discharge). The NHS Long Term Plan makes a clear commitment to identify and support unpaid carers.

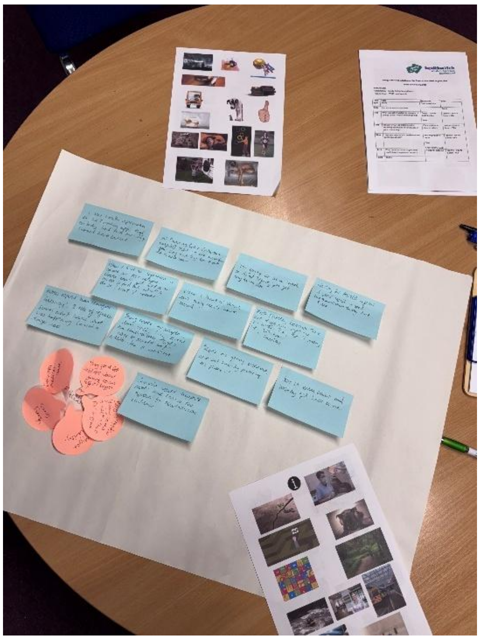
What we did

Healthwatch Windsor, Ascot and Maidenhead and Family Action Young Carers hosted an engagement event on 23rd January 2025. We followed this up with a short survey for those young carers and families who could not attend in person.

Family Action Young Carers support families where a child or young person between the ages of 5 – 18 years old is providing care for someone who has a mental health or physical illness, learning or physical disability or a difficulty with drugs or alcohol. By working together with local services, they reduce the caring tasks children and young people provide and support families to improve their child's health and wellbeing.

We received feedback from 19 people, including 11 family members and 8 young carers. Small groups took part in activities related to health and wellbeing.





What we heard

We asked families, what are your top priorities when receiving health and care services in your community?

Effective Communication and Listening: Many people emphasised the importance of being listened to, whether by healthcare providers, specialists, or family care teams. The need for timely responses to emails or voicemails and having appointments where patients are heard and understood was frequently mentioned.

> “Better communication, I often send emails to people providing care, or I will call and leave a voicemail message, and these don't get answered.”

> “I find that doctors don't remember that my child has Downs Syndrome unless I point it out with every interaction. They also don't know what it means – for example they ask me complex questions about symptoms, but his language is too limited for me to know.”

Timely Access to Care: Several individuals expressed frustration over long waiting lists for services, whether for specialist care or interventions. The desire for shorter waiting times and quicker action when promises are made stood out.

> “The ADHD waiting list is very long. I would like shorter waiting times for services.”

> “To be able to get an appointment at first place which has become impossible.”

> “At the moment they don't seem to read my notes and will not take the actions that I feel they should. I previously had care at a different hospital, and I thought it was much better.”

Personalised and Adapted Care: There is a strong focus on the need for care that is tailored to the individual, especially when it comes to supporting children with specific needs (e.g., disabilities, mental health). People want healthcare providers to make small adaptations, like adjusting lighting or treatment approaches, to meet the unique needs of each person. Better training for healthcare professionals on the needs of children with learning difficulties was highlighted.

> “It's really important to have people who understand and will do something a bit different to suit the child. Adapt to the actual person’s needs, everyone is an individual.”

“To be listened to and understood within a reasonable time scale. Having access to care with reasonable adjustments and resources available for children with disabilities - for example there’s not much help in the borough for autistic children who need specialist adjustments for procedures such as bloods but there are not resources available for this.”

“Medical and social care professionals who are educated in what learning difficulties are, and therefore what a child might or might not be able to do. Positivity from medical professionals - less "I’m sorry", and more "how wonderful is this kid"

“That it works for me and isn’t just a blanket response to a regular issue.”

“Having specialist clinics for children with autism / ADHD to care for obesity (related to sensory issues to do with their conditions) and routine tests which need extra adjustments such as blood tests.”

Mental Health and Emotional Support: Many parent carers highlighted the importance of mental health, both for individuals and their families, particularly in the context of caring for others. Emotional support, such as for young carers, and access to mental health resources are crucial components of wellbeing.

“I would like better mental health support, joined up care and records. Family care is really important for young carers.”

“Better family support, counselling and timely diagnosis.”

Support and Resources for Caregivers and Young Carers: Several people stressed the need for more support for caregivers, including respite, emotional support, and access to necessary resources for both children and adults. There was a call for more comprehensive family care options, easier access to necessary equipment, and more understanding from healthcare providers.

> “I would like emotional support for my daughter as a young carer. Access to respite and use of leisure facilities for us.”

> “Reinstating giving carers access to the time out card- this made a huge difference to us and is now unaffordable for us.”

> “Exercise and martial arts, in particular, really helps my kids. It's a constructive way to deal with discipline, manners and respect. I would like to see more activities for children. Young carers is great but would like other things too. I don't want my kids to think they're the only ones with a poorly mum.”

We asked young carers, what are your top priorities when receiving health and care services in your community?

Consistency and Continuity in Care: There was a strong desire for stability in healthcare, with respondents highlighting the importance of seeing the same healthcare professionals regularly. This is particularly noted in the context of mental health care (e.g., CAMHS), where building trust with a consistent provider helps with comfort and treatment effectiveness.

> “When I see CAMHS I want to see the same doctor regularly. If a new doctor comes every time, it makes me feel awkward. I'm really quiet so having to get to know someone new is difficult. They tell each other about my medication but it's not personal information so I have to retell my story. The longest I've ever seen someone was for 3 sessions. If you're not comfortable speaking to them it's hard for them to assess you and how can they know if you've improved if they don't know what you were like before?”

Qualified and Knowledgeable Healthcare Providers: Young carers told us about the importance of feeling confident in the skills and knowledge of healthcare professionals. This includes both confidence in diagnosis and treatment, as well as trust in their ability to handle complex situations.

> “I want to feel confident that people who work in healthcare know what they're doing because it makes me feel better.”

Comfortable and Supportive Environment: Many young carers mentioned the need for a more welcoming and relaxing environment, especially when discussing sensitive issues like mental health. A comfortable space can make individuals feel more at ease and help them open up.

> “The environment is important especially when I'm talking to people about my mental health. I want a comfortable space that's relaxing. Last time I went it was a small room with two chairs and a table, it felt almost like an interrogation.”

> “A smile and a nice person helps. When you arrive in the corridor just a good smile, maybe being made a hot drink, being made to feel comfortable.”

> “The space is important, a big room but not too big and good equipment, it helps when you're having tests.”

Access to Comprehensive Care: Young carers want a more streamlined approach to healthcare, where multiple appointments and tests are consolidated to minimize back-and-forth visits. This could reduce stress and improve the overall experience.

> “When I have hearing tests at hospital I have to go back and forth on different days. If I could just attend hospital once and have all the appointments that I need that would be much better for me.”

Stress Management and Emotional Support: Managing emotional stress is a key concern for many, particularly in balancing personal life and school or family pressures. There is a desire for outlets for stress relief, relaxation options, and support in dealing with emotional challenges.

> “Managing the stress of school with stress of home. Having an outlet for stress. Having some options for time out and relaxation.”

> “I need access to specialist counselling services who are aware of the challenges for young carers.”

> “Having a safe space to talk. Meeting other children who are going through similar situations.”

We asked families, have you experienced barriers to getting great care?

Poor Communication and Coordination: Many parent carers report difficulties with communication, including not being informed about important health information, or not receiving clear, timely updates from healthcare providers. Additionally, issues with coordination between different care teams and hospitals were highlighted, where different systems and unconnected records made care feel fragmented.

> “I saw health information on the Frimley app that nobody had told me about. They should have called and made sure I was aware.”

> “In Frimley healthcare there are different systems for notes, and they don't seem to match up for my family. I am receiving care at Wexham and from Frimley Park. Sometimes they don't seem to know what the other one is doing.”

Complex or Confusing Referral Processes: Respondents highlighted challenges with referral systems, particularly changes in processes that were not clearly communicated to schools or families. The need for better guidance and awareness from institutions involved in referrals to avoid delays or confusion was a recurring theme.

The way the ADHD referral process happens has changed, now there's a gateway and you need 2 sets of referrals. The school didn't know what was happening they thought they'd already filled in the forms. It caused a longer wait and I needed to tell them what was happening. If the process has changed, then schools need to be aware. Someone needs to make sure they know what they're doing.

Long Wait Times and Delays in Care: Long wait times for appointments, referrals, and follow-up care were frequently mentioned, with some individuals facing multi-year waits for services like ADHD referrals or delays in receiving necessary treatments. The waiting process itself often lacks proactive updates or communication.

“We've been waiting for an ADHD referral and been told it's a three-year wait. When I called, they seemed to know my child and communicated well. I do you think they should proactively contact me rather than waiting for me to ring and ask about the waiting times or tell them about additional needs for my child.”

“Yes, huge delays in CAMHS. Lack of total family support.”

“Listening and acting before a person gets to crisis point, - reductions of wait times for different care especially mental health.”

Access to Specialist Care and Support: There were reports of difficulty accessing specialist care, particularly in urgent situations. For example, some individuals struggled to contact specialists or were unsure of how to get their care transferred to more suitable facilities, affecting their overall health.

> “When I recently had an infection, it caused an MS relapse. My GP couldn't get hold of my MS nurse to find out what to do so I had to wait 2 weeks, and I felt really unwell. It's difficult to get hold of the MS nurse. At another hospital where I was treated previously there's one number that you rang, and they sort it out there and then.”

Lack of Understanding and Support for Specific Conditions: Several parent carers expressed frustration with the lack of understanding from healthcare professionals, especially when it comes to conditions like PDA (Pathological Demand Avoidance) or autism. Families affected by these conditions feel that healthcare workers are insufficiently trained to address their specific needs, leading to inadequate support.

> “Everything is disjointed. Very few professionals have heard of PDA (profile of autism) and barely anyone understands how difficult life is for families impacted.”

We asked young carers, have you experienced barriers to getting great care?

Generational Gaps and Understanding: There was concern about the lack of empathy or understanding from healthcare professionals who are from a different generation, especially regarding mental health issues.

> “Having a generational gap can be a problem. As for example a similar age can understand mental health, especially as they grew up in the same world with social media and things like that.”

Long Wait Times and Delays in Care: Young carers felt frustration with long wait times. Delays in receiving timely care create barriers and can worsen health conditions.

> “Waiting times are too long. There is a lack of care for mental health for children under 11.”

Support for young carers: Young carers told us about insufficient understanding of their role. Some individuals feel that people in positions of responsibility don’t recognise or understand the specific needs of young carers.

> “Yes - I've had headteachers tell me I'm not a young carer (even though my brother has Downs Syndrome). So, I feel there is inconsistency in people knowing what a young carer is.”

We asked families what improvements they thought would have the greatest impact?

The families identified these top 5 themes

- More accessible and diverse support activities for children and families
- Improved collaboration and seamless care between health and social services.
- Prevention and clear guidance on health concerns
- Specialised care and education for conditions like learning difficulties and autism
- Faster and more flexible access to health services

We asked young carers what improvements they thought would have the greatest impact?

The young carers identified these top 5 themes

- Welcoming and comfortable environment:
- Timely and accessible care
- Ongoing and specialist support for specific needs.
- Safe and supportive communication
- Consistency in care provided

These findings will be shared with Frimley Health Integrated Care System to be considered alongside other feedback received as part of the Reconnect, Reset, Rebuild project and will be presented to their board for consideration. We will update the public with any actions agreed at a later date.

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